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ABSTRACT

The paper describes the Iowa Plan, a network approach to providing home care services for children with handicaps and chronic diseases who require medical technology services. The Iowa Regional Child Health Center Network is reviewed. The centers are based on shared responsibility between major state agencies and the community and serve as focal points for a network of regional services. Three elements are seen to be essential to the system: (1) professional services provided by physicians and pediatric nurse practitioners; (2) administration and community organization; and (3) parent support and advocacy. Action steps for the transition of services from the hospital to the community are delineated. The program is explained to be cost effective because only one new position--the home care program coordinator--is required. (CL)

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THE IOWA PROGRAM TO PROVIDE COORDINATED SERVICES FOR CHILDREN WHO NEED TECHNICAL MEDICAL CARE IN THEIR HOME/COMMUNITY

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A Network Approach

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Fourth, Washington, DC, December 6-8, 1985

The Iowa Program to Provide Coordinated Services for Children
Who Need Technical Medical Care in Their Home/Community - A Network Approach

In an advertisement for computer hardware and software, AT&T states "no vendor in this market can be all things to all people. Someone has to be the "Integrator. Thats our Ace. We know how to make the pieces fit."

The Surgeron General's Conference, held in December, 1983, alerted those responsible for providing services for handicapped children that there is a new population of children with handicaps and chronic diseases who are with us because their lives have been saved by modern medical care. The point was also made that these children required ongoing and sometimes complex care and that some of them can and should receive their needed services in their home or in their community.

In order to receive such needed services in the home/community, a community care team must be assembled who knows how to make the pieces of a complex health care system fit into an integrated and coordinated whole.

The Iowa Plan is a network approach to the provision of home care services for technology-dependent children.

The pieces to provide home care are already present:

- Tertiary and secondary level hospitals and staff, with NICUs and PICUs.
- Medical technology - originally hospital-based and now adaptable to home and community use.
- Public programs who have been alerted to this population of children and their needs - Department of Human Services, Public Health, Special Education.
- Title XIX, with waivers for home cae, SSI, and insurance programs to provide out of hospital care.
- And, most important, willing parents who believe their children not only can but should be raised in their home and in their community.

The pieces are there. Someone has to be the integrator. Our position in the Iowa Child Health Specialty Clinics (formerly State Services for Crippled Children) is "we know how."

CHSC in Iowa has a statewide coordinated network of community-based regional child health centers, agreements with the Department of Human Services and Special Education, and working relationships with many volunteer community organizations. This innovative service system can be adapted to provide the needed support services for children with handicaps and chronic diseases who require complex forms of ongoing care.

Let me describe first the Iowa Regional Child Health Center network: The network was initiated in 1977, when the Iowa Crippled Children's Program first received a SPRANS grant from DMCH/PHS/HHS and was expanded with appropriations since 1981 from the Iowa State Legislature. These regional centers are multi-disciplinary in composition with the staff drawn from major state agencies (CHSC, Special Education, Department of Human Services, and Public Health) and from volunteer community health programs. Each center is under the policy-making direction of an advisory board. Interagency agreements between the major state agencies already exist. Each center is staffed by a pediatric nurse practitioner, secretary and a community-based pediatrician. Special education staff (usually psychologists) and liasion persons are assigned to each center. Social workers are assigned by the Department of Human Services. Public health, VNA, hospital and other community groups provide further support.

These centers are based upon the shared conviction that children with handicapping conditions are the shared responsibility of the major state agencies and the community. The center provides a neutral site where professionals drawn from the major agencies and health caring professions can assemble to provide diagnostic and evaluation services and to make possible case planning and coordinated services for the children and their families.

Each center serves also as the focus for a network of regional services. (See attachment)

In a relatively large semi-rural state with only three population centers of 100,000 or more, a statewide system to return children to their home or their community would be either prohibitively expensive or very difficult to implement if such a regional system of community child health centers was not already in place.

This point needs to be emphasized: if a statewide system for the care of handicapped children or children who have chronic disease and are dependent upon modern forms of high technology care can be made to work here in such a rural state, it can be made to work anywhere.

Essential to the system for children requiring modern forms of high technology medical care are three elements: (a) professional services provided by physicians, pediatric nurse practitioners, (b) administration and community organization, (c) parent support and advocacy. In the Iowa Plan, these essential elements are arranged as a part of a stratified system of health care in a carefully coordinated sequence of tertiary, secondary and primary/regional activities. The sequence for home care begins with those who can provide tertiary level care or secondary level care in ICUs and it continues into the community with primary level services coordinated and integrated involving the family, pediatric nurse practitioners from the CHSC program, and parent advocacy and support provided by SKIP representatives (Sick Kids Need Involved People).

1. Acute Level of Care (ICU) - Level III or Level II Hospital Responsibilities

   Provider: NICU or PICU staff -- services needed to achieve and maintain medical stability upon discharge.

(In the Iowa plan this level and these activities are assumed and are not detailed here. They are part of the patient's ongoing care in the NICU or PICU. The physician and/or neonatologist has primary responsibility for the child and overall responsibility for the discharge planning process.)

Action Steps: Hospital Staff & Program Coordinator

- identification and preparation of home care candidates;
- identification and preparation of family to provide home care;
- referral to CHSC's technical medical care program;
- develop medical discharge plan in cooperation with program coordinator and information provided by the regional PNP.

Family: Continual monitoring and encouragement of the family's interest and involvement with the child. Consistent with good medical care, every effort must be made to maintain or increase the family's emotional bonding with the child. Frequent visits are to be encouraged, caring for the child's routine personal needs when possible, frequent reports on the child's condition. Important is the assumption by both providers and the family that eventually the child will be returned to his/her home.

Action Steps: Program Consultant for Parents

- Parent advocacy
- Assist families with financial planning
- Identify and monitor the activities of local SKIP personnel

2. Program Coordinator and Discharge Planning

The CHSC program coordinator reviews the case with the discharge planner and/or staff as soon as possible.

Action Steps:
- cooperate with the staff of the referring hospital in the creation of the medical discharge plan;
- initiates funding alternatives for home care;
- supervise regional PNPs activities in developing and implementing the patient's medical discharge plan in the community's support service network plan;
- arrange for the initial home visits;
- supervise the regional PNPs preparation of a community plan of care.

3. Parent Advocacy Support by SKIP Representative

Ongoing emotional support, encouragement and advocacy for the family is a vital role assigned to the SKIP representative.

Action Steps:
- parent advocacy;
- negotiate with other state programs about the provision of local services;
- identify and monitor the activities of local SKIP personnel.

Primary/Regional Level of Care

Providers: When a discharge date has been identified, the regional/community care team is assembled by the regional PNP and meets with the program coordinator.

a. Regional Plan of Care

The regional plan of care is an adaptation of the medical discharge plan to local circumstances by the regional PNP, the program coordinator and the community care team.

Components of the regional plan of care are:

a. equipment and supplies;
b. community services (emergency medical care, utilities, fire department, police);
c. home nursing care and other needed therapists;
d. special education services depending upon the child's needs and age;
e. specification of the family's role and responsibility.

b. The community care team includes some or all of the following:

- the family's local physician, hospital home health care staff -- AEA, DHS, emergency support personnel, PHN/VNA, SKIP, equipment vendors

Action Steps:
- make arrangements for the implementation of medical discharge plan
- organize the community support service network
- plan. (If local resources are not available, PNP will inform central program coordinator.)
- monitor the initial home visits;
- serve as case manager to implement medical discharge plan and community support service network plan.
- make home visits by the regional PNP, SKIP representatives and social worker to assess family functioning, household needs and conditions, parental involvement and capabilities.

To Conclude:

The 1970's was the decade of "mainstreaming" and "least restrictive environment" for thousands of children throughout the nation. These children had labels such as "developmentally disabled," "mentally retarded," "learning disabled," etc. In the 1980's health care professionals became aware of a new population of children in need of a similar approach to the services which they require. These are the children who are "graduates" of neonatal and pediatric intensive care units. These children have survived infancy due to highly sophisticated medical skills and technology. Yet these children cannot be "mainstreamed"

nor returned to the "least restrictive environment"--that is, to their own homes, communities, and schools--without the medical/health skills and equipment upon which their very life depends.

To date, the answer to the provision of the complex services needed by this population of children has been to retain them in the tertiary centers where they have received their original treatment until they are functionally independent or until they can live in their home to receive the same services as traditionally provided the chronically ill child.

The Iowa program attempts to coordinate into a stratified system the efforts of the professionals responsible for providing tertiary, intermediate and primary levels of health care with the parents and the people and programs in the community who provide other necessary support services.

The Iowa Plan will be cost effective, utilizing existing staff from the Iowa Crippled Children's program and the other state agencies. Only one new position is required - the home care program coordinator. Existing interagency agreements and local operating practices provide the base for coordinated efforts on both the state and community level.

The result of the Iowa Plan is a system that makes it possible for many of the children who need medical and health technology to find a place in their homes and communities that is indeed the least restrictive one for them.

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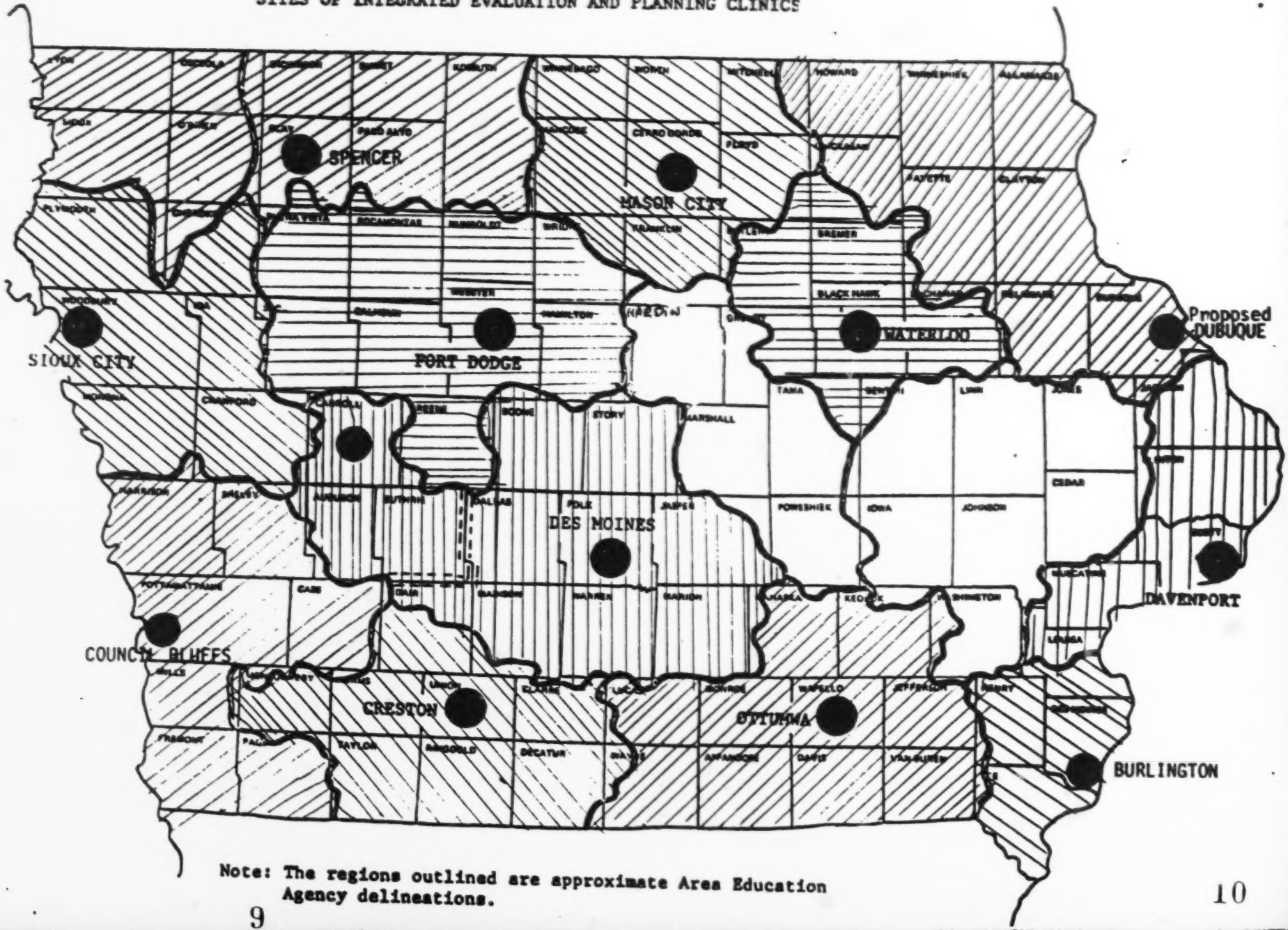
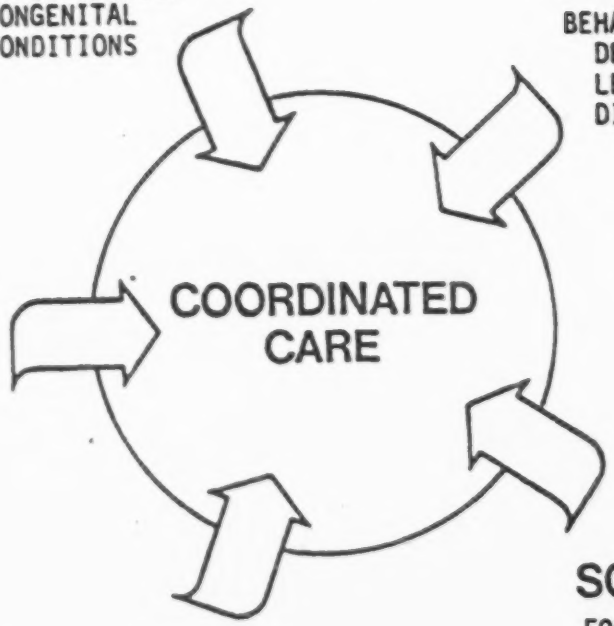
SITES OF INTEGRATED EVALUATION AND PLANNING CLINICS



Note: The regions outlined are approximate Area Education Agency delineations.

VOLUNTARY COALITION



MEDICAL COMMUNITY

ACUTE, CHRONIC,
CONGENITAL
CONDITIONS

EDUCATION AND SCHOOL RELATED

BEHAVIORAL,
DEVELOPMENTAL,
LEARNING
DIFFICULTIES

PUBLIC HEALTH

HEALTH
SUPERVISION
HOME VISITS
SCREENING

SOCIAL SERVICES

FOLLOW-UP
PLACEMENT
FINANCIAL HELP
CATEGORICAL
PROGRAMS

FAMILY

NUTRITION
HEALTH
SUPERVISION
COMPLIANCE

FEDERAL

(Office of Maternal & Child Health)
MCH CC SIDS Hemophilia Genetics

Child Abuse | Title I Program | Head Start | Voc Rehab | WIC Program | Migrant Program | Day Care

STATE

Dept. of Health: MCH SIDS Health Education Genetics WIC

Board of Regents: CC SSI

Dept. of Human Services: EPSDT Child Abuse DD-MR

Dept. of Public Instruction: Special Education

Volunteer Health Programs

STATE AGENCY COORDINATING COUNCIL

REGIONAL GOVERNMENT

Dept. of MCH Regional Office

Crippled Children's Program Regional Office

Dept. of Human Services Regional Office

Dept. of Public Instruction Regional Office

COMMUNITY CHILD COUNCIL

COMMUNITY

1. MCH & PH Basic Child Health Services
   - Well Child Clinic
   - Immunization Program
   - WIC
   - Genetics Clinics
2. Education
   - Child Find
   - Special Education "related services"
3. University Hospitals
   - Iowa High Risk Follow-up Program
   - Hemophilia Program
   - Division of Pediatric-Cardiology

COMMUNITY NETWORK OF SERVICES

Jointly Conducted Community Programs
- Regional Integrated Evaluation & Planning Clinics (1-2-4-5)
- Child Sexual Abuse Prevention Program (2-4-5)
- Scoliosis Screening Program (2-4-6)
- Speech and Hearing Consultive Services (2-4)
- Nutritional Counseling Program (1-4)
- Home Care Program (2-4-5-6)
- Clinic Transportation Program (4-5)
- Lead Screening (1-4)
- Satellite Clinic Program (1-2-4-5)
- High Risk Follow-up Program (3-4)
- 0-3 Program (2-4)
- Pediatric Coronary Disease Prevention Program (3-4)
- Hemophilia Follow-up (3-4)

4. Child Health Specialty Clinics
   - Statewide Mobile Clinics
   - Adolescent Services
5. Department of Human Services
   - Medicaid
   - Waiver Programs
6. Volunteer Health Programs

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COMMUNITY SYSTEMS PROVIDING CHILD HEALTH CARE | PRIVATE MEDICAL CARE SYSTEM | PUBLIC EDUCATION SYSTEM | PUBLIC SOCIAL SERVICES SYSTEMS | LOCAL HEALTH/HOSPITAL SYSTEMS

SPECIAL EDUCATION P.L. 94-142

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CHSC PROGRAM TO PROVIDE SERVICE FOR CHILDREN REQUIRING SPECIALIZED MEDICAL CARE IN THE HOME

UNIVERSITY HOSPITALS NICU/PICU

IOWA REGIONAL HOSPITALS NICU/PICU

1. Assist in conducting education programs for Regional PNP.

Hospital Based Responsibilities:

1. Identify children who are candidates for home care.
2. Identify and prepare family to provide home care.
3. Refer to CHSC specialized medical home care program.
4. Develop medical discharge plan in cooperation with program coordinator using information provided by the regional PNP.

CHSC Specialized Medical Home Care Program

Program Coordinator

Program Consultant For Parents

Administrative Responsibilities:

1. Monitor the reporting & evaluation system to maintain quality assurance.
2. Conduct a continuing education program for regional PNPs to assure they will have the skills needed to assure quality care.

Program Responsibilities:

1. Cooperate with the staff of the referring NICU/PICU in the creation of the medical discharge plan.
2. Supervise regional PNPs activities in developing and implementing the patient's medical discharge plan in the community's support service network plan.
3. Arrange for the initial home trial visit.
4. Supervise the regional PNP activities.

Family Responsibilities:

1. Parent advocacy.
2. Assist families with financial planning.
3. Identify and monitor the activities of local SKIP personnel.

Regional PNP

Regional Consultant For Parents

Regional Administrative Responsibilities:

1. Identify local personnel and resources needed to provide home care as recommended in the medical discharge plan.
2. Convene case planning conferences of local providers to create community support service network plan.
3. Designate who will be responsible for providing "hands on" care to maintain quality assurance.
4. Work with members of the community support service network to assure that services are coordinated.
5. Monitor records that are kept for reporting and evaluation system.
6. Serve as liaison person between members of the the community support network care team.

Regional Patient Care Responsibilities:

1. Make arrangements to implement the medical discharge plan.
2. Organize the community support service network plan. (If local resources are not available, PNP will inform central program coordinator.)
3. Monitor the initial home trial visit.
4. Serve as case manager to implement medical discharge plan and community support service network plan.

Regional Responsibilities:

1. Assist families to examine home care options.
2. Provide direct family support.

Community Support Services Network Team

The Child's Family and

Child's Physician (a)	Hospitals (b)	AEA (c)	DHS (d)	Emergency Support Personnel (e)	Community Home Care Programs (f)	Local SKIP (g)	Equipment Vendors (h)

Local Case Plan Responsibilities:

(a) Provide primary medical services for acute care and crisis intervention.
(b) Make acute hospital care available and lifeline for patients from home to appropriate hospital.
(c) Provide a variety of educational, stimulation and related service programs in the home.
(d) Pay for services provided children eligible for public financial assistance.
(e) Assure that transportation and required services as electricity, etc. will be available on a 24-hour basis.
(f) Supervise or provide "hands on" patient care in the home by contract.
(g) Provide support to family with advice and counsel.
(h) Be available on 24-hour call to provide or service equipment used in home care.

——— Patient care responsibilities
------ Administrative responsibilities
..... Consulting responsibilities

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The Iowa Plan for Home Care Technology Dependent Children

Referral Process

Re: Joint arrangements between the Department of Human Services and Child Health Specialty Clinics for prospective Title XIX "waiver" children.

I. DHS process - If the first contact is to DHS, the DHS procedures will be followed.

II. CHSC process - If the first contact by the child's family/hospital/physician, etc. is to CHSC, the following procedures willl be followed:

1. Referral

   a. If written, the referral will be received by Medical Records Center, data entered, foldered, and forwarded to Program Coordinator.

   b. If by phone, the referral will be received by Program Coordinator with Patient Management backup in her absence. A CHSC referral form will be prepared, sent to MRC, data entered, foldered, and returned to Program Coordinator.

2. Intake

   a. Program Coordinator gathers data -- patient history, discharge summary, specific needs, etc.

   b. Program Coordinator determines family need for financial assistance.

3. Possible Need for "Waiver"

   a. Program Coordinator contacts the county DHS, income maintenance worker by phone who will verify/establish financial eligibility. The IM worker then refers family to service worker for care planning.

   b. Program Coordinator mails patient materials as requested to social worker.

   c. Program Coordinator tracks waiver process and assists social worker as needed until waiver determination is made (at least weekly).

4. Care Plan Development

   a. Program Coordinator meets with facility discharge planning team and others as identified (SKIP representative, family, etc.).

   b. Prior to child's discharge Program Coordinator notifies regional PNP and supplies discharge planning details in order to initiate community planning including DHS case worker.

c. Regional PNP identifies members of community team including DHS case worker, adapting discharge plan to reflect community implementation.

d. Program Coordinator finalizes discharge plan with the team.

5. Entry Into the Community

a. Trial visit(s) arrangements are coordinated via the Program Coordinator, PNP and implementing team.

b. Trial visit(s) assessed by PNP with input from community care team.

c. Plan adjusted as needed by PNP, Program Coordinator and care team.

6. Ongoing follow-up to maintain adequacy of plan

a. There will be medical review by regional physician once per month or more frequently if needed.

b. PNP makes status report to Program Coordinator bi-monthly for first three months and at least monthly thereafter until stability is achieved.

c. Copies of status reports sent to DHS social worker as requested.